

Research Article

Development of community participation indicators to advance the quality of spinal cord injury rehabilitation: SCI-High Project

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Context: Community participation following spinal cord injury/disease (SCI/D) can be challenging due to associated primary impairments and secondary health conditions as well as difficulties navigating both the built and social-emotional environment. To improve the quality of SCI/D rehabilitation care to optimize community participation, the SCI-High Project developed a set of structure, process and outcome indicators for adults with SCI/D in the first 18 months after rehabilitation admission.

Methods: A pan-Canadian Working Group of diverse stakeholders: (1) defined the community participation construct; (2) conducted a systematic review of available outcomes and their psychometric properties; (3) constructed a Driver diagram summarizing available evidence associated with community participation; and (4) prepared a process map. Facilitated meetings allowed selection and review of a set of structure, process and outcome indicators.

Results: The structure indicator is the proportion of SCI/D rehabilitation programs with availability of transition living setting/independent living unit. The process indicators are the proportion of SCI/D rehabilitation inpatients who experienced: (a) a therapeutic community outing prior to rehabilitation discharge; and, (b) those who received a pass to go home for the weekend. The intermediary and final outcome measures are the Moorong Self-Efficacy Scale and the Reintegration to Normal Living Index.

Conclusion: The proposed indicators have the potential to inform whether inpatient rehabilitation for persons with SCI/D can improve self-efficacy and lead to high levels of community participation post-rehabilitation discharge.

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Introduction

One of the main markers of successful rehabilitation following spinal cord injury/disease (SCI/D) is enabling an individual's transition from inpatient clinical care to the community where a person can fully participate in diverse social roles.¹ For instance, meaningful participation in occupations or employment and/or the ability to engage in societal roles holds significant implications for one's health and well-being,² is internationally recognized as a fundamental right for all persons, including those with a disability³ and represents an emerging policy goal.⁴ The most widely used definition of 'Participation' is the one provided by the International Classification of Functioning, Disability and Health (ICF), which defines it as 'involvement in a life situation'.⁵ Although there is considerable debate regarding the nuances of what constitutes participation,⁶ there is growing recognition that it is "multifaceted and influenced by perceptions, desires and choices".⁷ Moreover, participation encompasses a number of aspects of an individual's life related to their social health and wellbeing, such as engagement, enfranchisement, a sense of agency at both the personal and societal level, and having social connections.⁸ For many persons with SCI/D, however, the ability to fully participate in their community is often made difficult by their primary impairments and secondary health conditions⁹ and because of the lack of accessibility to both the built and social environment.^{10,11} One possible contributing factor to community participation, such as challenges in accessing transportation,¹² undertaking leisure/recreational activities,¹³ and returning to work,¹⁴ is that people with SCI/D often feel unprepared when being discharged from the inpatient setting back to the community.^{15,16}

With the end goal of rehabilitation being to facilitate community participation, an evidence-based approach should be used by rehabilitation professionals to ensure they are providing person-centered care; however, a recent review demonstrated that most studies are of low methodological quality.⁶ A 2012 environmental scan of Canadian rehabilitation hospitals found that standards are emerging regarding the programs, services and equipment required during SCI/D inpatient rehabilitation to facilitate community participation.¹⁷ Unfortunately, there is regional disparity regarding the existing programming and the availability, capacity and complexity of outpatient

services offered by rehabilitation sites to support community participation.¹⁷ Some of the noted barriers included a lack of dedicated resources and rehabilitation service providers, and unclear and/or cumbersome referral processes. These processes can be further complicated by a lack of access to third-party funding that can provide additional supports to enhance community participation outcomes.^{17,18} Given the relatively poor levels of available evidence to inform clinical practice and the disparity of care to support community participation post-SCI/D, there is a need to formulate an approach that builds upon a growing consensus for quality measures to support decision-making in healthcare.¹⁹

The SCI-High Project is a Canadian wide quality improvement initiative to advance knowledge and clinical care for several domains of SCI/D rehabilitative care. It aims to establish 11 sets of structure, process and outcome quality indicators for care domains during the initial 18 months following admission to inpatient SCI/D rehabilitation.²⁰ The decision to use quality indicators as a driving force for national change is based on their efficacy in identifying trends, informing priority setting and policy formulation, and for monitoring rehabilitation programs and care processes.¹⁹ Moreover, the use of indicators enables decision-makers to undertake comparisons across different healthcare settings while also supporting quality improvement; all of which are promote transparency in healthcare.²¹ Hence, the objective of this specific quality improvement initiative is to describe the development of the SCI-High Community Participation indicators.

Methods

The SCI-High Project is a quality improvement initiative to advance the quality of rehabilitation care that intuitively followed from a prior environmental scan (E-Scan) of SCI/D rehabilitation services in Canada conducted between 2009 and 2012.^{22,23} The E-Scan contained 17 Domain-specific national report cards summarizing the current state of knowledge, clinical standards, and policy, which highlighted the gaps between knowledge generation and clinical application in SCI/D rehabilitation. Using the modified Hanlon method (a well-respected technique to objectively rank health priorities based on defined priority criteria and feasibility factors) and UCLA/RAND consensus methods,^{24,25} the top 11 prioritized SCI/D

rehabilitation Domains were identified, which included Community Participation. A detailed description of the overall SCI-High Project (www.sci-high.ca) methods and process for identifying ‘Community Participation’ as a priority domain are described in related manuscripts.^{20,26} The development of the ‘Community Participation’ domain’s structure, process and outcome indicators followed a modified approach to that described by Mainz,¹⁹ which included: (a) formation and organization of the national and local Working Groups; (b) defining and refining the key domain and specific target construct; (c) providing an overview/summary of existing evidence and practice; (d) developing and interpreting a Driver diagram; and (e) selecting indicators (structure, process and outcome indicators).

Structure indicators encompass the properties of a setting in which healthcare services are delivered²⁷ while *process indicators* describe the specific activities undertaken in providing and receiving care.²⁸ *Outcome indicators* describe the effects of healthcare to a specific individual or population (e.g. patient satisfaction, health-related quality of life, etc.).²⁸ Throughout this process, a facilitated discussion occurred amongst the domain specific Working Group and the SCI-High Project Team to utilize relevant expertise on the topic, while ensuring that the broader goals of the SCI-High Project were aligned across the other 10 domain Working Groups (as appropriate). The selected indicators will be integrated into the larger Project framework to create a group of indicators and related best practices for routine implementation within a single rehabilitation program with project-wide report cards enabling cross site comparisons of structure, process and outcomes.

Community participation working group

Experts and relevant stakeholders were invited to participate in the SCI-High Project as members of the Community Participation Working Group based on their knowledge of SCI/D rehabilitation, community participation, health service delivery, employment and patient education. Hence, we formed a group ($N = 13$) composed of practitioners, physiatrists, partners from community organizations, policy leaders, rehabilitation scientists, researchers and a stakeholder with lived experience. From this Working Group, representation from the Canadian provinces of British Columbia, Alberta, Saskatchewan, Ontario and Quebec was obtained. The Working Group met nine times via conference call over a 30-month period, totaling ten hours of discussion related to the development

and refinement of the indicators. Outside of the formal meetings, individual members of the Working Group completed an additional review of the prepared materials, shared resources and/or practice standards with one another.

Evidence Map, Construct Definition and Selection of Indicators

The selection of Community Participation as a domain of interest emerged from a consensus-building activity to select the broader set of domains being pursued within the overarching SCI-High Project.²⁰ When developing and selecting indicators, it is also critical to not solely rely on expert opinion but to also be grounded on empirical data.²¹ Consequently, a comprehensive literature review and intake of existing resources and guidelines pertinent to community participation post-SCI/D was undertaken, which included identifying a list of available community participation outcome measures (see [Table 1](#)).

This initiative involved a systematic search to collect information about SCI/D rehabilitation care related to community participation, identification of factors that influence the outcome of rehabilitation interventions, and a scoping synthesis of the data acquired. MEDLINE and EMBASE and CINAHL databases were searched using the terms “community participation”, “community integration”, “spinal cord injury”, or both. This information was then used to create a Driver diagram to illustrate known drivers or factors that impact community participation among individuals with SCI/D ([Fig. 1](#)). A Driver diagram is a visual display of a high-level quality improvement goal, and a set of underpinning factors/goals.⁴³ The branches in red within the final Driver diagram represent the main areas that were the focus for development of indicators based on experts’ opinions (see [Results](#) for full description).

With regard to quality indicators, the Working Group was asked to develop/select at least one indicator each for structure, process and outcome that would improve community participation for patients with SCI/D. The Project Leaders stipulated that the indicators should be relevant, concise and feasible to implement nationally. For instance, this might be as easy and quick as indicating the presence of a structure indicator one per year or collecting outcome indicators that could be collected in 10 min or less per patient. Ideally, the indicators could be measured using established or new measurement tools (*i.e.* questionnaires, data collection sheets, laboratory exams, and medical

Table 1 Community participation outcome measures.

Measurement tool	Number of items	Score or scale	Psychometric properties			Access link
			Construct	Cost	Reliability / Validity	
Assessment of Life Habits Scale (LIFE-H) ²⁹	298 (short version: 77)	Mobility items include 18 items (short version LIFE-H); To calculate a single item, score the answers related to the difficulty level and assistance are combined and weighted to derive an accomplishment score.	Life habits and handicap	Must be purchased	Adequate to excellent reliability (ICC from 0.67 to 0.83); Poor to excellent validity (correlation with CHART from 0.14 to 0.89)	here
Craig Handicap Assessment & Reporting Technique (CHART*) ³⁰	32 (short form: 19)	Each domain or subscale has a maximum score of 100 points.	Handicap (used as a proxy for participation)	Public Domain	Test re-test reliability: excellent ($r = 0.93$) for the total score and ranges from adequate to excellent for the domains (moderate: $r = 0.53$ for Physical Independence to high: $r = 1.00$ for Economic Self-sufficiency).	here
Craig Hospital Inventory of Environmental Factors (CHIEF) ³¹	25	Scores are calculated by multiplying each item with the frequency score (range: 0–4) by magnitude (range: 1–2) to yield an overall “impact” score (range: 0–8).	Environment	Public Domain	Excellent test-retest reliability for total CHIEF (ICC = 0.93); Excellent sub-scale test reliability (ICC range = 0.77–.89)	here and here
Community Integration Measure (CIM**) ³²	10	Each item is scored on a 5-point Likert scale from 1 (always disagree) to 5 (always agree).	Community Participation	Public Domain	Internal consistency: excellent (Cronbach’s alpha = 0.87); Concurrent validity with the CIQ: moderate ($r = 0.34$);	here and here
Impact of Participation and Autonomy Questionnaire (IPAQ*) ³³	39	Each item is scored on a 5-point rating scale from 1 (very good) to 5 (very poor).	Participation	Public Domain	Test-retest reliability: excellent; Convergent Validity: Poor correlation between the IPA domain of autonomy outdoors and the Sickness Impact Profile’s physical dimension ($r = 0.29$); Discriminant Validity: Poor correlation between the IPA Scale domains and the London Handicap Scale domains ($r = -0.29-0.01$); High ceiling effect.	here
Leisure Time Physical Activity Questionnaire for People with Spinal Cord Injury (LTPAQ-SCI) ³⁴	6	Items with various weights capture activity levels.	General community	Public Domain	Weak to moderate correlation magnitude ($r = 0.27-0.54$) for intensity scales with intensity within LTPA PARA-SCI scale; ICC = 0.83 (95% CI: 0.69-0.91)	here
Life Satisfaction Questionnaire (LISAT-11) ³⁵	11	Each item is scored on a 6-point scale from 1 (very dissatisfied) to 6 (very satisfied).	Life Satisfaction (Domain Specific)	Public Domain	Adequate internal consistency (Cronbach’s alpha = 0.74)	here
Moorong Self-Efficacy Scale (MSES) ³⁶	16	Each item is scored on a 7-point scale from 1 (very uncertain) to 7 (very certain). The total scale score is obtained by calculating the sum of the individual scores with a range from 16 to 112.	Participation	Public Domain	Excellent internal consistency (Cronbach’s alpha = 0.93)	here

Continued

Table 1 Continued

Measurement tool	Number of items	Score or scale	Psychometric properties			Access link
			Construct	Cost	Reliability / Validity	
The Physical Activity Recall Assessment for People with Spinal Cord injury (PARA-SCI) ³⁷	5 domains	Data are reported as an average number of minutes of activity per day (mild, moderate, heavy, total) for the two dimensions (Leisure-time physical activity or lifestyle activity) and a cumulative index over a 3-day period.	Activity including participation	Public Domain	Intraclass correlations ranged from 0.45 to 0.91; correlations between PARA-SCI scores and indirect calorimetry estimates of activity ranged from 0.27 to 0.88.	here
Physical Activity Scale for Individuals with Physical Disabilities (PASIPD) ³⁸	13 (alternate 11 items)	The average hours per day for each item is multiplied by a metabolic equivalent (MET).	Activity (self-care)	Public Domain	Poor internal consistency (Cronbach's alpha = 0.37–0.65); Poor to excellent Content & Construct validity	here
Person-Perceived Participation in Daily Activities (PDAQ) ³⁹	26	Each item is scored on a 4-point scale from “yes-as much as I want” to “no- I don't want to do it” Participants describe their participation in DAs in the last 12 months.	Participation	Public Domain	The PDAQ provides a comprehensive assessment of participation without considerable respondent burden.	here
Reintegration to Normal Living Index (RNLI)** ⁴⁰	11	Each item is scored using a 10 cm visual analogue scale anchored with phrases (0: no reintegration, 10: complete reintegration).	Participation	Public Domain	Excellent internal consistency (Cronbach's alpha = 0.87); Construct Validity: Excellent correlations between the RNLI and Quality of Life Index (QLI) ($r = -0.654$); Adequate correlation between the RNLI and Functional Independence Measure ($r = -0.348$)	here
Risk Inventory for persons with Spinal Cord Injury (RISCI) ⁴¹	12	Each item is scored on a 5-point scale from 0 (not risky at all) to 4 (extremely risky).	Risk Tolerance	Unknown	Excellent internal consistency (Cronbach's alpha = 0.86)	here
Spinal Cord Independence Measure (SCIM) ⁴²	16 (Mobility: 5)	Each item is scored on a 5-point scale and the total score is the summation of all items.	Activity (outdoor mobility)	Public Domain	Total interrater agreement on the various individual tasks ranged between 72 and 99%; for most of the SCIM tasks, total agreement was higher than 85%, and the Kappa coefficient ranged between 0.66 and 0.98.	here

record data), depending on the requirements and feasibility of a given indicator.

Results

Construct Definition

Similar to the processes followed by other SCI-High Working Groups,⁴⁴ the initial process for ensuring that the development and selection of indicators would be grounded in either theory and/or evidence was to review the construct definition and to use the Driver diagrams to critically reflect upon it. Following review of the systematic searches, discussions of other

conceptualizations/definitions of community participation, and multiple refinements of the Driver diagram, the group agreed that ensuring individuals living with SCI/D are healthy, able and provided opportunities to participate fully in the life situations they deem important was the driver most likely to advance SCI/D rehabilitation care in the near term. Consequently, the group decided that grounding the construct within the (World Health Organization)⁵ was important since it is widely recognized internationally but that examples of ‘life situations’ also be included with the definition to illustrate different

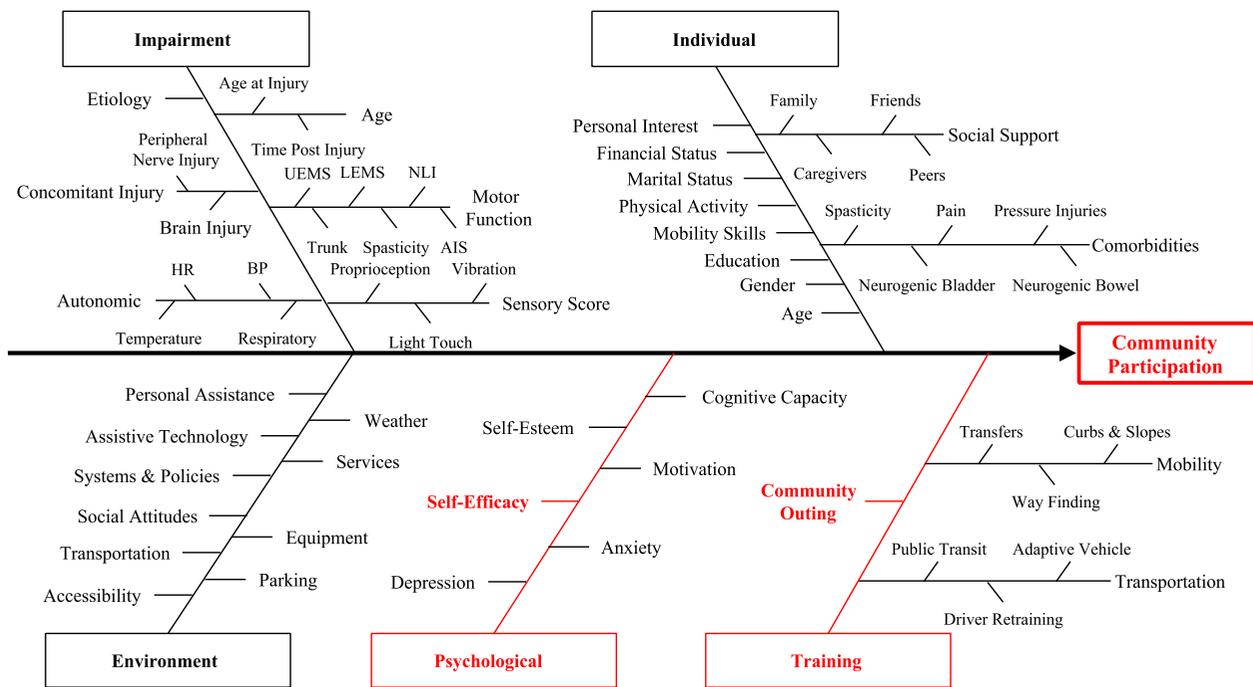


Figure 1 Community participation Driver diagram. The impairment branch is common to the 11 SCI-high project domains. UEMS: Upper-Extremity Motor Score, LEMS: Lower-Extremity Motor Score, NLI: Neurological Level of Injury, AIS: ASIA Impairment Scale; HR: Heart Rate, BP: Blood Pressure.

aspects of participation, such as self-care, relationships with others, and engaging in other personal and professional roles. These additions were felt important given there is considerable debate about the construct and measurement of community participation.^{8,45-47} Based on these discussions, and reflection upon current terminology, the following construct definition was adopted:

Community participation is a broad construct defined by the World Health Organization as involvement in life situations. Within the ICF, a life situation encompasses several areas, including an individuals' ability to move around their home and community, bathe and dress themselves, engage in relationships with others, participate in social activities and civic life, in addition to employment, education, recreation and leisure activities.

It should be noted that although employment is included as part of the construct definition, the Working Group made the decision to create a separate definition, aim and subset of indicators for employment.⁴⁸ This was due to employment being a more targeted aspect of community participation that the group felt merited additional reflection and intervention as employment rates post-SCI/D are low.^{49,50} The Working group also felt that promoting quality

improvement in this sub-domain could lead to better outcomes for those individuals interested in returning to work. As well, return to work may not be relevant to the growing number of older adults who sustained their SCI/D when they had already retired or were close to doing so pre-injury. Identifying employment as a separate sub-set of the Community Participation Domain does not ascribe a higher value over other domains of community participation (e.g. recreation/leisure activities), but rather, underscores its complexity and importance of in terms of the potential for vocational re-training, need for special adaptive equipment, workplace accessibility and accommodations, employment schedule recommendations, and other financial considerations, such as loss of public or private third party funding.⁵¹

Indicator Development

The selection and refinement of structure, process and outcome indicators related to the Community Participation domain were primarily driven by the impetus to promote community participation (including enhanced self-efficacy) with the goal to empower the individuals with SCI/D to participate fully in the life situations they deem important and ensure successful community integration (Fig. 1 and the construct definition). The decision to focus on these aspects on the Driver diagram were

further reinforced by the decision to create a separate set of indicators for employment, and there was already a set of indicators on emotional wellbeing.⁴⁴ Table 2 summarizes the denominators, type of indicator and timing of measurement for each of the indicators selected by the Community Participation Working Group.

With regard to the *structure indicator*, the Working Group selected the proportion of SCI/D rehabilitation programs with availability of a transition living setting/ independent living unit. Transitional living units (TLUs) are primary rehabilitation services that are provided either in the patient’s own home, or in a home-like setting that is separate from the inpatient hospital environment, prior to transition to living in the community.⁵² Transitional rehabilitation services are an innovative approach to promoting continuity of care by enabling people with SCI/D to access support as required but provides them with an opportunity to: (a) re-establish family relationships that have been disrupted due to inpatient hospitalization and the need to assume or alter caregiving relationships;⁵³ (b) develop a sense of personal control and direction in their daily lives; (c) hone newly acquired skills related to the management of their SCI/D in a ‘real world’ context; and (d) develop problem-solving strategies to circumvent access and integration issues associated with returning to home.⁵²

Relatedly, the selected *process indicators* were the proportion of SCI/D rehabilitation inpatients who experienced: (a) a therapeutic community outing prior to rehabilitation discharge; and, (b) those who received a pass to go home for the weekend. With regard to a community outing, this could involve a patient participating in a formal excursion into the community accompanied by healthcare professional, such as a recreation therapist, where there is an opportunity to participate in a recreation/leisure activity and/or to practice newly acquired skills (e.g. accessing transportation). A therapeutic community outing involves joint goal setting, advance planning and an assessment of goal attainment following the therapeutic outing by the individual with SCI/D and their rehabilitation service provider. The Working Group created the Community Therapeutic Outing Documentation Form (Fig. 2), which allows healthcare professionals to document elements related to a community outing, such as transportation, patient safety assessment, and a pre-outing perspective. The form also allows for individuals with SCI/D to select from agreed upon community outing goals (e.g. accessing transit, adaptive equipment, directing care,) between themselves and therapists that they would like to achieve during their community outing, followed by an evaluation of these goals. A therapeutic outing is distinct from an event where an individual spontaneously elects to leave the rehabilitation center

Table 2 Selected structure, process and outcome indicators for the community participation domain.

Indicator	Denominator	Type	Time of measurement
Proportion of SCI/D rehabilitation programs with availability of transition living setting/ independent living unit	Total number of participating tertiary SCI/D rehabilitation programs	Structure	Annual
Proportion of SCI/D rehabilitation inpatients who had a community outing prior to rehabilitation discharge	Total number of SCI/D patients discharged per FY	Process	Rehabilitation discharge
Proportion of SCI/D rehabilitation inpatients who went on a weekend pass prior to rehabilitation discharge	Total number of SCI/D patients discharged per FY	Process	Rehabilitation discharge
MSES	Total number of SCI/D patients discharged per FY	Outcome – Intermediary	2 weeks prior to rehabilitation discharge
MSES	Total number of SCI/D patients discharged per FY	Outcome – Intermediary	3 months (± 1 month) post rehabilitation discharge
RNL	Total number of SCI/D patients discharged per FY	Outcome – Intermediary	3 months (± 1 month) post rehabilitation discharge
MSES	Total number of SCI/D patients discharged	Outcome – Final	18 months (± 1 month) post rehabilitation admission
RNL	Total number of SCI/D patients discharged	Outcome – Final	18 months (± 1 month) post rehabilitation admission

Notes: FY = Fiscal Year; MSES = Moorong Self-Efficacy Scale; RNL = Reintegration to Normal Living Index.

Community Therapeutic Outing Documentation Form



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Outing Date:		Venue(s):	
Accompanied by:	<input type="checkbox"/> Recreational Therapist <input type="checkbox"/> Occupational Therapist <input type="checkbox"/> Physiotherapist <input type="checkbox"/> Other: _____	<input type="checkbox"/> Family/Friend <input type="checkbox"/> Personal Support Worker <input type="checkbox"/> Peer Support	
	<input type="checkbox"/> Public Transit (Bus, Train) <input type="checkbox"/> Accessible Public Transit <input type="checkbox"/> Wheelchair Accessible Taxi <input type="checkbox"/> Taxi <input type="checkbox"/> Other: _____		Pick-up Time: _____ Return Time: _____
Patient Safety Assessment	Health related issues/concerns <small>(Ex. AD, IC management)</small>	<input type="checkbox"/> Discussed: _____ <input type="checkbox"/> Not Applicable	
	Self-awareness, insight, social issues/concerns <small>(cognitive, social, communication)</small>	<input type="checkbox"/> Discussed: _____ <input type="checkbox"/> Not Applicable	
	Dietary needs	<input type="checkbox"/> Discussed: _____ <input type="checkbox"/> Not Applicable	
	Medication management	<input type="checkbox"/> Discussed: _____ <input type="checkbox"/> Not Applicable	
	Equipment needs	<input type="checkbox"/> Discussed: _____ <input type="checkbox"/> Previously Owned <input type="checkbox"/> Hospital Equipment <input type="checkbox"/> Not Applicable	
	Mobility- Outdoors	<input type="checkbox"/> Requires total assistance <input type="checkbox"/> Needs partial assistance and/or to operate manual or power wheelchair <input type="checkbox"/> Moves independently in manual or power wheelchair	
	Mobility- Indoors	<input type="checkbox"/> Requires total assistance <input type="checkbox"/> Needs partial assistance and/or supervision to operate manual or power wheelchair <input type="checkbox"/> Moves independently in manual or power wheelchair	
Transfer	<input type="checkbox"/> Requires total assistance <input type="checkbox"/> Needs partial assistance and/or supervision and/or adaptive devices <input type="checkbox"/> Transfers independent with or without adaptive devices		
Pre-outing Patient Perspective	Please document patient's comments and perspectives regarding the planned community therapeutic outing in advance of the event		

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Figure 2 SCI-High community therapeutic outing documentation form. Created for healthcare professionals to document elements related to community outing and agreed upon goals between patient and therapist to achieve during community outing.

Community Therapeutic Outing Documentation Form



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Please select 1-5 agreed upon goals that the patient and therapist would like to achieve during the community outing from the table below.

Agreed Upon Community Outing Goal(s)	Education	<input type="checkbox"/> Accessibility <input type="checkbox"/> Architectural/physical obstacles <input type="checkbox"/> Accessing the transit system <input type="checkbox"/> Transportation needs <input type="checkbox"/> Adaptive equipment	<input type="checkbox"/> Personal care supplies <input type="checkbox"/> Selecting appropriate attire (e.g. weather, event, ease of donning, skin integrity, etc.) <input type="checkbox"/> Self-image <input type="checkbox"/> Money management <input type="checkbox"/> Other: _____
	Skills training	<input type="checkbox"/> Wheelchair safety & mobility <input type="checkbox"/> Surfaces (<i>Curbs, inclines, ramps, etc.</i>) <input type="checkbox"/> Transfers <input type="checkbox"/> Door management <input type="checkbox"/> Elevators <input type="checkbox"/> Escalators <input type="checkbox"/> Inclement weather <input type="checkbox"/> Personal care <input type="checkbox"/> Problem solving techniques <input type="checkbox"/> Advocacy/Assertiveness	<input type="checkbox"/> Directing care <input type="checkbox"/> Social interaction & communication <input type="checkbox"/> Energy conservation & endurance <input type="checkbox"/> Time management <input type="checkbox"/> Stress management <input type="checkbox"/> Coping strategies <input type="checkbox"/> Emotional adjustment <input type="checkbox"/> Other: _____ <input type="checkbox"/> Other: _____ <input type="checkbox"/> Other: _____

Evaluation of Goal Attainment:	Not Achieved	Partially achieved	Fully achieved	Comments/New Goal Identified
Goal 1:				
Goal 2:				
Goal 3:				
Goal 4:				
Goal 5:				

Post Outing Patient Perspective /Satisfaction	<i>Please document patient's comments, perspectives, and satisfaction related to goal achievement following the community therapeutic outing</i>
Incidental Findings/ Subjective Clinical Impressions	

Data Collection Details:			
Name: <i>(please print)</i>		Date Completed:	YYYY-MM-DD

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Fig. 2 Continued

unaccompanied, with no pre-planning or post event evaluation of the therapeutic value of the outing. Weekend passes have been recommended as methods

to facilitate transition to home from inpatient rehabilitation by providing patients and family members the opportunity to practice living within their home

environment prior to discharge from rehabilitation. By going home for a minimum of 2 days/2 nights (e.g. Friday evening to Sunday evening) under the supervision of a family member, the person with SCI/D might identify and resolve problems that could develop after discharge.

To demonstrate the effectiveness of SCI/D rehabilitation programs for promoting better community participation outcomes, the Working Group selected *outcome indicators* that could help ‘predict’ who may be at risk for poor outcomes. A key mechanism associated with improved outcomes following SCI/D, such as community participation, is self-efficacy⁵⁴⁻⁵⁶; (see Driver diagram – Figure 1). *Self-efficacy* is defined as the individual’s belief or confidence in his/her abilities to successfully execute the necessary behavior to produce the desired outcomes in the future.⁵⁷ Thus, the Moorong Self-Efficacy Scale (MSES)⁵⁸ was selected as an intermediary outcome measure to be administered to SCI/D patients prior to inpatient discharge, 3 months post-discharge and at 18 months-post rehabilitation admission.

The MSES is a scale designed for the SCI/D population that asks individuals to rate their confidence in their ability to perform 16 tasks (e.g. *I can avoid having bowel accidents, I can deal with unexpected problems that come up in life, etc.*) using a seven-point Likert type rating scale (1 = very uncertain to 7 = very certain). Scores range from 16 to 112, with a score of 89 or higher being indicative of high levels of self-efficacy.⁵⁹ The MSES has been validated for the SCI/D population.^{60,61} In addition to the MSES being designed and validated for SCI/D, the selection of this measure was deemed useful for identifying persons with low self-efficacy, which may put them at greater risk for poorer community participation.

To assess community participation, the Reintegration to Normal Living (RNL)⁶² Index was selected as the final outcome measure. The RNL Index is an 11-item measure of community reintegration that covers such areas as participation in recreational and social activities, movement within the community, and degree of comfort the individual has in his/her role in the family and with other relationships. The scale has a few scoring options but we selected the 3-point scoring system (0 = does not describe my situation; 1 = partially describes my situation; and 2 = fully describes my situation), with a score of 17 or higher being indicative of high levels of participation.⁶³ The 3-point version was selected since it has been validated for the SCI/D population,⁶³ and data collection over

the telephone⁶⁴ and is also the version used as part of the Canadian’s Institute for Health Information (CIHI)’s National Rehabilitation Reporting System,⁶⁵ which collects data from adult inpatient rehabilitation facilities and programs in nine provinces across Canada.

Discussion

The SCI-High initiative established a set of structure, process and outcome indicators to assess community participation in adults with SCI/D in the first 18 months after inpatient rehabilitation admission. The Working Group grounded the conceptual definition of participation using the ICF classification since it is a widely used and internationally recognized framework that has been successfully applied to examine outcomes in persons with SCI/D at the individual, clinical and policy level.⁶⁶ Based on available evidence and expert opinion, the selected indicators (structure, process, and outcome) were deemed to be feasible, clinically relevant and likely to have the most impact on making a meaningful change in inpatient rehabilitation practice for the SCI/D population.

With regard to the structure indicator, the selection of whether a rehabilitation site has a TLU was based on making a bold statement regarding the inequity of available structures to promote community participation across the country.¹⁷ For instance, the Toronto Rehabilitation Institute’s Brain and Spinal Cord Rehabilitation Program at the Lyndhurst Centre (Ontario), which has Canada’s largest SCI/D rehabilitation inpatient and outpatient programs, has a separate living unit within the hospital where patients can practice living in an ‘apartment’ with their family member(s) to obtain a brief reprieve from living in a hospital room with other patients. Alternately, other organizations have separate freestanding apartments with accessible equipment for patients and families to use or rent. Unfortunately, these types of units and/or programs are not commonplace across the country. Hence, the selection of this structure indicator is designed in part to highlight the importance and value of TLUs and to showcase the disparity of availability across the country. It is hoped that this will spur further action for other sites in other provinces to develop their own TLUs.

The process indicators describing the proportion of SCI/D rehabilitation inpatients who experienced a therapeutic community outing prior to rehabilitation discharge and those who received a pass to go home for the weekend were selected to give patients opportunities to apply knowledge and skills gained in

rehabilitation in ‘real-world’ settings. In both instances, these process indicators should involve working with the patient with SCI/D to establish a goal with either their community outing and/or weekend pass. Ideally, the rehabilitation period should be one where there is active collaboration between the person with SCI/D and the rehabilitation team to set goals,⁶⁷ which can serve to identify the person’s needs, values and expectations regarding the rehabilitative process.⁶⁸ There is evidence that goal setting may also lead to improved adaptation to disability in persons recovering from stroke⁶⁹, and this may also be applicable to persons recovering from SCI/D.⁶⁹

Unfortunately, a recent review by Maribo *et al.*⁷⁰ that examined the qualitative SCI/D literature on rehabilitation goal-setting found that despite being advocated by health professionals, collaborative goal setting did not always translate into actual practice; with goals tending to be skewed towards physical function. Consequently, some studies indicated that persons with SCI/D did not feel adequately prepared for returning home to deal with the long-term challenges of SCI/D, including vocational, financial and social domains.⁷⁰ A key argument related to collaborative goal-setting put forth by some of the studies included in this review,⁷⁰ was that establishing meaningful goals (which may extend beyond recovery of physical functioning) could lead to strengthened autonomy and self-efficacy in persons with SCI/D.^{71–73} Hence, the use of setting goals with a community outing and/or weekend pass may promote a means for fostering a more collaborative approach to goal-setting between healthcare professionals and persons with SCI/D thereby leading to enhanced community participation outcomes.

The selection of the MSES as an intermediary outcome measure is one that is relatively easy and quick to administer but that is also validated to assess self-efficacy and is highly predictive of community participation outcomes post-SCI/D. For some individuals, the actual (or perceived) limitations associated with their SCI/D may significantly affect the injured individual’s belief in his/her capability to successfully participate in day-to-day activities.^{61,74} Individuals with high self-efficacy demonstrate active problem-solving and decision-making skills.⁷⁵ Conversely, decreased self-efficacy has been associated with depression and anxiety,⁷⁶ and lack of adherence to health and disease self-management,⁷⁷ which can impede successful adjustment to community living post-SCI/D.⁵⁵ Importantly, self-efficacy is a modifiable construct⁷⁸ and improvements in individuals’ self-efficacy have been used as a mechanism to enhance community

integration⁷⁹ and self-management behaviors among those individuals with SCI/D.⁸⁰ Unfortunately, there is evidence suggesting that self-efficacy among many individuals with SCI living in the community is suboptimal.⁷⁴ Thus, if rehabilitation is effective in enhancing self-efficacy, which may include opportunities to practice in real-world settings (e.g. community outing), then it increases the likelihood of better community participation post-rehabilitation discharge.

Finally, the selection of the RNL Index as the final outcome indicator is one that has a number of useful features for SCI/D in the Canadian rehabilitation context, which includes its adoption by provinces collecting health administrative data.⁶³ More importantly, the RNL Index is one of the few subjective measures of social participation¹ that is brief and easy to administer. In contrast to the objective perspective of participation, which is focused on the extent to which persons with chronic health conditions are restricted from participation by comparing their status, activities and lifestyles with those of persons of comparable backgrounds (e.g. age, sex, etc.) from the general population, subjective measures emphasize the individual’s preferences to better understand their particular needs and problems.⁸¹ Hence, using the RNL Index provides a more person-centered approach to assessing the degree of how persons with SCI/D view their ability to participate in their community.

To support the national implementation of the SCI-High indicators, a meeting was held with managers of Canadian rehabilitation centers that deliver services to patients with SCI/D to review the proposed indicators for all domains, including community participation. The outcome of that meeting was their commitment to explore the adoption and implementation of the potential indicators at individual rehabilitation hospitals. One potential challenge with the roll-out of the indicators is that they have not yet been piloted, which is an important aspect of indicator development.¹⁹ However, our Working Group comprised of diverse stakeholders from across the country anticipate that this set of indicators are likely to be well-received given that they should be easy to move into practice without significant additional burden to clinical care and their prior validation in the SCI/D population. Regardless, there will be opportunity for refinement and an implementation science approach (*i.e.* specifying what, when and how)⁸² will be used to identify the barriers and facilitators that different sites will need to consider prior to routine implementation of the community participation. In particular, this refinement period may provide opportunities to gain more input from people

with SCI/D about the selected indicators as well as to explore the roles of family caregivers in supporting community participation, which was a stakeholder perspective missing from our Working Group. As well, there may be geographic discrepancies across Canadian rehabilitation sites that may require more flexibility on how the structure and/or process indicators are recorded since larger sites in urban settings may have a large number of patients and resources to easily implement them compared to smaller rural settings; thereby leading to a more graded set of options for the site. As well, the advent of the COVID-19 pandemic has altered rehabilitation service delivery across the country and has limited the ability of rehabilitation programs to support therapeutic community outings and transitional living due to concerns regarding community exposure, staff and patient safety. It is likely that the pandemic may make the need for these services more challenging to justify to policy-makers and funders alike. Hence, the selected indicators will be vital to demonstrating the interconnectedness of specific domains within SCI-High and the anticipated strong associations between therapeutic outings, self-esteem and “good” community participation.

Conclusion

In summary, the use of structure, process and outcome indicators to support community participation across Canadian SCI/D rehabilitation centers holds the potential for promoting better practices to enable persons with SCI/D to optimize participation in the community post-discharge. Although the emphasis of the SCI-High initiative is a quality improvement project, the opportunity to analyze longitudinal data on changes in self-efficacy within the first 18 months from rehabilitation admission and to link it to community participation may help advance research in this domain, which has generally been found to be of low methodological quality.⁶ Arguably, the community participation domain will be the most meaningful in demonstrating impactful change for SCI/D rehabilitative care since it will be indicative of the collective impact and efficacy of the other SCI-High domains (*i.e.* Cardiometabolic Health, Emotional Well-Being, Sexual Health, Tissue Integrity, Urinary Tract Infection, Walking, Wheeled Mobility, Self-Management, Reaching, Grasping and Manipulation, and Employment)^{44,48,83–90} being implemented across Canada.

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